cal profession is sought to render opinions about an individual's needs. Disability assessments are an example. We are also involved in welfare decisions, child placements, insurance eligibility and other situations in which we apply our skills for purposes other than to care for the patient.[12]

It is true that our assessment may help the individual, such as a truly needy patient who receives disability benefits. But it is also possible that we may contribute to a decision not to render benefits. Such a decision can be quite disruptive of the doctor-patient relationship. The risk arises because these are nonclinical uses of medical skills—beneficence lost.

The contemporary transformation of the delivery of medical care could further erode the principle of beneficence as a premier ethical premise of the medical profession. More and more, physicians are finding themselves in institutional relationships. In contrast to the prison or military or industrial physician, the institutions do not seem to be at cross-purposes with our professional mission. They are institutions, such as health maintenance organizations and other managed-care entities, whose purpose is to organize health care for patients. Problems will arise because institutions serve groups. Physicians care for individuals. The principle of beneficence is more important than ever as a guide to our practice of medicine.

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Consent for Children as Organ Donors

Rodney W. Williams MD, JD

The use of children as organ donors has been a source of legal and ethical concern since transplantation became generally available.

Introduction

The number of diseases in children successfully treated by bone marrow and solid organ transplantation continually increases. The availability of a histo-compatible minor sibling as a donor has raised ethical and legal issues since transplantation became available. Organ donation represents a significant risk to one child (the donor) while the benefit accrues to a second child (the recipient). Parents who decide for both children must deal with this conflict.

St Francis Medical Center has devised a consent procedure that attempts to avoid parental conflict of interest, recognizes the emerging competency of the child donor, and provides a measure of protection for the donor.

Reprints are available from the author:
St Francis Medical Center
2230 Liliha Street
Honolulu, Hawaii 96817

Sophie's Choice

In *Sophie's Choice,*[1] a mother was forced to decide which of her two children would be killed in a Nazi concentration camp. Early commentators portrayed parental consent for their child's organ donation similarly, refusing to acknowledge that organ donors benefited from the donation:

> [T]he parents should not be allowed to deprive a child of one of his vital organs without his consent or his intelligent comprehension...[I]t is considered almost impossible to support the view that parents should be allowed to consent to the removal of organs from minor children. Actually, legislation should be passed to prohibit children under a certain age from acting as donors.[2]

The Supreme Court of the United States in a different context has stated that while parents may be free to become martyrs themselves, it does not follow that they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.[3]

Parents are given broad authority to enter into contracts for their children and to consent to medical treatment. Since organ donation is not medical treatment, however, consent should not extend to procedures such as organ donation where the benefit accrues to one child while the risk is borne by a second. Does the decision presented to the parents differ from Sophie's choice only in degree and not in kind?

Solomon's Decision

In one of the earliest recorded cases involving disputed parentage, King Solomon, without the benefit of DNA testing, awarded custody of the child to the mother who acted in the child's best interest by refusing to consent to the child's hemicorpectomy.[4] The courts have adopted this standard routinely approving intrafamily donation and recognizing that the organ donation actually would be in the best interest of the donor.

In Kentucky, in the case of *Strunk v. Strunk*,[5] a 27-year-old mentally incompetent ward of the state was the only medically acceptable kidney donor for his 28-year-old brother. Psychiatric testimony in that case supported the court's conclusion that the donation would be beneficial to the incompetent because the psychological benefits and the continuing close relationship of the siblings outweighed the minimal risks of the procedure.

Similarly, in a 1979 Texas case,[6] the court authorized the mother of a 14-year-old girl to consent to the donation of one of her kidneys to her brother, again finding the "substantial psychological benefits" of donation outweighed the minimal risks involved.

In other circumstances involving family members, the courts have refused to authorize the procedure when no benefit could be demonstrated. In one of these cases,[7] the father of twins sought to compel testing to determine if they were suitable donors for their half-brother, his leukemic son. The mother of the twins had never been married to their father and had sole care and responsibility for the twins. The court, in refusing to allow the twins even to be tested as potential donors, noted that, though the potential donors and recipient shared the same biological father, there was no evidence that they had or would have a close relationship and, therefore, there was no benefit to the potential donors.

Similarly, a Wisconsin court was asked to authorize a kidney donation from a catatonic schizophrenic to his sister. After hearing testimony that the donor was "indifferent to his environment" and that his disease was a "flight from reality," the court refused consent, finding that there was absolutely no evidence that any interests of the ward would be served by the transplant.[8]

The American Medical Association in a Code of Ethics report agreed with the *best-interest* approach when it made the following statement:

> The merits of a best-interest standard include its ability to incorporate the preferences of children as evidence of what is in their best interests without relying solely on a fictional determination of what they would want were their values more mature. Best interest also allows for the consideration of potential psychological benefits, when they exist, and weighs the medical risks of transplantation, rejecting transplantations which pose an unacceptably high risk to the minor source...[E]vidence of future benefit to the minor source should be clear and convincing. Possible benefits to a child include the following: Continued emotional bonds between the minor and the recipient; increased self-esteem; and prevention of adverse reaction to death of a sibling. Whether a child will capture these benefits depends on the child's separate circumstances.[9]

The AMA position recognizes the benefits to the donor, but also concedes that these benefits are not absolute and must be balanced against the risks. A decision about bone-marrow donation is comparatively easy—there have been no deaths associated with the procedure, and the bone marrow regenerates. Kidney transplant involves the permanent loss of a kidney and a higher perioperative mortality. According to Livingston Wong MD at St Francis, eight kidney donors have died in the perioperative period. Would the benefits described in this excerpt justify a lung donation?

Judicial Procedure

Early skepticism about the value of organ donation to the donor paralleled a societal debate about the proper forum in which such bioethical concerns could be addressed. A Massachusetts court[10] in discussing the use of a guardian *ad litem* to make decisions for the mentally incompetent, as opposed to the patient's family and family physicians and hospital committees stated:

> We take a dim view of any attempt to shift the ultimate decision-making responsibility away from the duly established courts of proper jurisdiction to any committee, panel or group, ad hoc or permanent...We do not view the judicial resolution of this most difficult and awesome question... as constituting a 'gratuitous encroachment' on the domain of medical expertise. Rather, such questions of life and death seem to us to require the process of detached but passionate investigation and decision that would form the ideals under which the judicial branch of government was created. Achieving this ideal is our responsibility and that of the lower court, and is not to be entrusted to any other group purporting to represent the 'morality and conscience of our society,' no matter how highly motivated and or impressively constituted.

When consent for the minor donor is sought through the legal system, the court usually appoints a guardian *ad litem* to represent the child's interest. A guardian *ad litem* would typically determine that the procedure was necessary; the risks to the donor were minimal; the donor was willing to help his or her sibling; the parents were fully informed about the risks to the donor and consented. The judicial process also involves other steps that are time consuming and costly to the patient, the hospital, and the health care providers involved.

After careful evaluation of the guardian *ad litem* process and discussion with Mainland transplant centers, St Francis Medical Center decided the judicial process was too cumbersome, time consuming, and costly. The medical center now uses an alternative procedure to the traditional judicial system. The objectives are 1) to adequately consider the interests of the prospective minor donor; 2) to utilize impartial advocates who have no involvement in the bone marrow transplant procedure; 3) to be expeditious, because of the time pressures created by the instability of the potential recipient's illness; and 4) not to impose additional financial or emotional burdens on the family already under stress because of the seriousness of the illness.

This alternative procedure utilizes an ad hoc committee, which is different in each case. The committee consists of a child psychiatrist/psychologist, a pediatrician, and another member of the medical staff with no direct interest in the case. The committee members are chosen for their ability to communicate with children and their knowledge of child development.

The proposed donors are interviewed individually by the committee in a supportive environment to determine their understanding of their role in the transplant procedure and whether or not their decision-making is free from duress and based on adequate information. The interviewing process is informal and begins with questions about the donor and his or her interests. The committee asks how the decision to donate was made and if he or she wants to donate.

One concern of the committee is the degree of parental influence on the potential donor. Recently, an ad hoc committee was chatting informally with a minor donor and her parents prior to an individual meeting with the child. All attempts to engage the donor, a 14-year-old, failed. When asked a question, she would frequently shrug noncommittally or look at her parents who were quick to answer for her.

While meeting with the committee alone, the child readily disclosed her fears regarding the procedure, especially the needle sticks involved, as she had already undergone one bone marrow biopsy and aspiration.

Q (from a committee member): Well, have you talked about these fears with your parents?

A: Yes.

Q: And what did they say?

A: They said, "You must be strong."

Clearly the parents were not giving this adolescent much room to make her own decision.

The committee explored the family structure a little farther and found that there was a grandmother who was a prominent member of the family and a significant person in the life of the donor.

Q: Did you discuss this with your grandmother?

A: Yes.

Q: And what did she say?

A: She said I could do whatever I wanted and I didn't have to do this if I didn't want. It was my decision and she would still love me.

On further questioning with the donor, she disclosed a similar conversation with her recipient sister.

Q: And what did your sister say?

A: She also said that I should make my own decision and that I didn't have to do it if I didn't want to.

Q: And what did you decide?

A: I decided to help my sister. We fight a lot, you know, but I still want to see her get better and help if I can.

Based on the conversation about the grandmother and recipient, the committee decided that she did make her own decision to support her sister. She was able to articulate her fears and talk about the pressure from her parents but still had sufficient presence of mind to consult other significant family members and, most important, her recipient sister. Her conversation about her fears, her parents, her grandmother, and her sister undoubtedly mirrored the conflicts in her own psyche. Articulating the pros and cons in the manner she did and making a choice convinced the committee that the child was indeed mature enough to make this decision and that the parental influence, though a factor, was not determinative.

Conflict of interest usually occurs when the parent or parents are asked to put a healthy child at risk to assist the ill child. However, it can also occur when the child is asked to be the donor for a parent. One father, when asked about the decision to use his child as the donor for his wife, the child's mother, responded, "Of course there is a conflict. Although the risk is minimal for my child, there is still a risk. The risk for my wife is high, but there is still a chance. But he said he wanted to do it no matter what. He knows the risks and he also understands that no one else can be the donor. The major conflict is not with me, but with my son. If he decides not to be the donor, his mother will die; if he is the donor, he will experience some discomfort, but he has the knowledge that he tried to help her. Doesn't that outweigh any risks or conflicts?"

The case went to the ad hoc committee. The committee agreed that the child was very knowledgeable about the transplant procedure and all of the risks involved. The child did not experience any adverse reactions from being the donor.

The ad hoc committee has been utilized only for minor donors who were developmentally appropriate for their age. The procedure could also be used for developmentally delayed donors. Adult retarded patients, however, may present a different set of issues as they may already be under the care of a guardian or a ward of the state. In that scenario, the decision would be made by the responsible entity. Nonetheless, the ad hoc committee would still be an appropriate forum in which the guardian could obtain the information necessary to make the decision for the ward.

Although the use of the ad hoc committee has been effective in Hawaii, it may not be as effective in other states where *ohana* is not as important. The committee is efficient and less costly than the judicial system, but is not without its problems. Such problems include finding members who are willing to participate, are available on short notice, and who are qualified.

Although the ad hoc committee may not be the universal answer, it does provide a forum in which the particular needs of the child donor can be more accurately determined and addressed than under the traditional judicial system.

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